

Reference Number:	100-17-DD
Title of Document:	Family Involvement
Date of Issue:	January 22, 1988
Effective Date:	January 22, 1988
Last Review Date:	February 1, 2008
Date of Last Revision:	February 1, 2008
Applicability:	Regional Centers, DSN Boards and Other Community Service Providers

REVISED

PURPOSE

This directive establishes guidelines for the involvement of the parents, legal guardians, or family representatives in the development and delivery of services by the Department, county DSN boards and community service providers. Additionally, this directive presents a summary of issues that deal with involvement and interaction with families whose members are being served by the Department.

STATEMENT OF PHILOSOPHY

People with disabilities are people first, and have the same rights as others. Just as is the case in other families, direct parental/family involvement in the making of major life decisions will vary in relation to the age and the abilities of their children. Parents of service recipients in their minority years are expected to assert more control and direction than are the parents of adult service recipients. People with limited experience and knowledge sometimes need training and support in order to make appropriate choices and exercise rights throughout their lives.

Families, friends and close associates provide vital supports in preparing people to exercise rights and assume responsibilities. Increasing competence in decision-making is a life-long process, which is enhanced by interaction with and support from the people closest to us.

Parental/family involvement and participation in all aspects of programming and services for people with disabilities is a normal, appropriate and desirable course. The person receiving service's welfare, growth and happiness are the mutual responsibility and concern of the service recipient himself/herself, the family, the Department, DSN Boards and service/support providers.

The Department will support the family unit and, whenever possible, people will be served as close to their family and home communities as possible.

Families are encouraged to maintain contact and involvement with their family member. Family involvement and participation in mutual planning with the Department, DSN Boards, and service providers facilitate decisions and service plans that serve the best interests and welfare of the people who receive services.

CONSUMER RESPONSIBILITIES

To the extent adults receiving services are competent to plan and direct their lives; they bear responsibility for their own happiness and success. Therefore, to the fullest extent possible, they should receive the training, experience and opportunity to make decisions and exercise rights. For those service recipients who are either still in their minority years or who are not capable of planning and directing their lives, parents/family members play a critical role as substitute decision makers.

When a person receiving services is deemed to need a guardian or other substitute decision maker, assessments should be done to determine the service recipient's specific range of abilities with regard to decision making so that guardianship or substitute decision-making does not extend beyond the areas needed. Furthermore, the need for guardianship or substitute decision-making should be periodically reviewed.

Decision-making should be returned to the service recipient if improvement in skills or a change in personal situation occurs over time. Although guardianship or substitute decision-making puts legal limits on the service recipient's exercise of certain rights, it does not prevent the person from participating in and influencing decisions or exercising other rights.

FAMILY RESPONSIBILITIES

Families are encouraged and expected to participate actively in the learning, growth, and development process of their family member. Such involvement includes participation in major decision-making processes affecting the person receiving services. With the concurrence of adult service recipients, families should attend meetings involving the person, keep the Department or DSN Board/service provider informed of any programmatic, medical or financial changes that might affect the status of the service recipient and work with the team to ensure that appropriate services and supports are being provided.

Families are encouraged to become involved in organizations that exist for people receiving services/family. These organizations provide support, promote understanding among families, and are a forum for exchange of information and ideas among the Department, DSN Boards/service providers and families.

If it becomes necessary or appropriate for placement in a community residential alternative or departmental regional center, families are encouraged to maintain active involvement through visitation and other forms of contact. Families should participate in team meetings, monitor the service recipient's service plan/s, and actively participate in the service recipient's future service and support needs as appropriate.

DEPARTMENT AND DSN BOARD OBLIGATIONS AND RESPONSIBILITIES

The family is an integral part of a person's life and with the concurrence of the adult service recipient, the Department and DSN Boards/service providers shall support and encourage a continuing relationship with all families. To facilitate this, support services will be developed which assist families in managing and maintaining their family member in their own home as long as may be desirable. Services may include, but not limited to, service coordination, early intervention, family support services, respite care, and day/employment services-

The Department and community service providers will work with local Departments of Social Services and/or courts to involve families to the extent possible when their family member is under court order or protective services.

For those people without any family involvement, organizations for people receiving services/families affiliated with DDSN regional centers and DSN Boards/service providers should develop family/volunteer contacts to assist the service recipient where necessary in advocating for his/her program needs.

The Department and DSN Boards/service providers will facilitate family involvement in the following ways:

Intake and Eligibility Process - Applicants and parents/guardians/family representatives will be invited and encouraged to participate in the intake and eligibility process by assisting in obtaining needed medical, educational, and social information. If the applicant is not eligible for services of the Department, the Service Coordinator will assist the applicant/family with recommended referrals.

Orientation For Persons Entering Programs - All programs and services will establish procedures for orientation of new service recipients and their families. This orientation will include:

- introductions to the facility, staff, services/programs offered and any cost associated with the provision of services
- visits/tours of available programs/services
- information about various advocacy and family/service recipient organizations These will include local organizations as well as the South Carolina Protection and Advocacy System and the State Ombudsman's Office
- a copy of this directive and any other policies, as requested, relevant to the roles and responsibilities of service recipients and their families
- the Service Recipient's Rights and Responsibilities Statement
- SCDDSN's Internal Grievance/Appeal Procedures

Additionally, each DDSN regional center, DSN Board/service provider is required to develop and distribute a service recipient/family handbook or information packet, which includes the above items directly or information about such.

Visitation - Once a person enters a program/service, and with the concurrence of adult service recipients, the parents/guardians/family representatives may visit at any reasonable time depending on the situation and services being provided. Prior notice is encouraged in the interest of the service recipient's privacy and in maintaining program

schedules. Programs should establish guidelines to facilitate family visitation and opportunities should be made available for families to visit in private.

Family visitations may be restricted or limited when it is determined by court order or by the circle of support to be in the service recipient's best interest for safety and security reasons. Any such restrictions must be reviewed at least annually by the Human Rights Committee and the service recipient and his/her family have the right to request a review of any such decision made by the support team. Restriction or limitation of family visits shall not be used as a form of discipline or behavior management.

Service Recipient's Planning Meetings – With the concurrence of adult service recipients, the parents/guardians/family representatives are considered to be a member of the person's circle of support and must be invited to participate in the meetings if the person chose to have a meeting. The meetings will be scheduled per the service recipient's choice and so that family representatives can attend if the service recipient so desires/chooses. If family representatives are unable to attend, an opportunity for input will be given to them. With the concurrence of the adult service recipient, a copy of the completed service plan/s will be sent to the parents/guardians/family representatives and interpreted for the family if they were not in attendance at the meeting and/or need assistance in understanding the Plan.

Parents are required by law to participate in the individual education plan (IEP) of their school-aged child. Parent surrogates will be appointed through legally established procedures when there is not a parental representative.

Communications – Service providers will establish effective channels of communication in order to keep parents/families informed. With the concurrence of adult service recipients, procedures for informing parents/guardians/family representatives of the service recipient's activities, serious behavior problems, any significant changes in their medical condition or serious incidents that may require special services or interventions will be developed. Notification will also be given if the person receiving services is involved in any unusual occurrence or critical incidents such as alleged incidents of abuse or neglect, or has a serious illness or accident.

With the concurrence of service recipients, the parents/guardians/family representatives shall have an opportunity to talk with staff directly involved in the delivery of services to the person.

Parents/guardians/family representatives are encouraged to take an active part in the delivery of services and supports. This includes periodic review of progress on goals and objectives established in the person's service plan/s.

Informed Consent - In cases where a proposed activity or procedure will create significant risk or harm, have a potentially irreversible impact, or intrude physically, psychologically or socially on the person receiving services, parents and legal guardians will be required to give informed consent on behalf of the service recipient whenever the service recipient is under 18 years of age or is incapable of providing consent.

If the service recipient is over 18 years of age, incapable of providing informed consent and there is no legally appointed guardian, then consent is sought according to Procedural Directive 535-07-PD.

Release of Records and Confidentiality - All personal information including information contained in an automated database, will be considered confidential and privileged as required under the Health Insurance Portability and Accountability Act (HIPAA) and, if applicable, the Family Educational Rights and Privacy Act (FERPA). However, upon the written request of or through a signed release by the person receiving services or legal guardian, records/information may be released to appropriate parties.

Additionally, records may be inspected and the service recipient, parent or legal guardian shall have the right to question the relevance and appropriateness of information in the record. Procedures shall be established for requesting a review of the inclusion of information in the record.

Service Recipient/Family Organizations - Each DDSN regional center and DSN Board/service provider will establish a Service Recipient/family organization. These groups serve as a communication link and facilitate understanding between providers and people receiving services. They also play an important role in providing a supportive resource among families following the birth of and during adjustment to a family member with a disability. These organizations may become involved in advocacy issues affecting people with disabilities in a service area and in fund-raising events that assist local programs.

As part of DDSN's overall Quality Assurance program, DDSN regional centers and DSN Boards are required to develop a consumer review panel to review services from a service recipient/family perspective. It is recommended that these panels develop tools to assist or provide structure in their review of services and get approval from DDSN or the DSN Board for their use. It is also recommended that non-DSN Board service providers develop similar review panels as described above.

Human Rights Committee - Each DDSN regional center, DSN Board and service provider shall establish a Human Rights Committee (HRC) to review behavioral support programs or treatment interventions as required by Departmental policy or licensing regulations. Representation on the HRCs will include parents/family representatives and people receiving services.

Service Recipient Grievance/Review Procedure - All programs and services will develop written procedures for the service recipient or his/her representative to request a review of agency decisions when there is concern that the action taken is not in their best interest. These procedures will be consistent with Procedural Directive 535-11-PD.

Behaviors related to a person's disability or family complaints about a program are not sufficient reasons for a service provider to ask that a service recipient be removed from the program. Every effort shall be made to address behaviors, and may include the development of a behavioral support plan. No one can be terminated from a program or service without consultation and concurrence of the Associate State Director for Policy and the Associate State Director for Operations.

Although the provider cannot, without consultation and concurrence by the Department, remove a service recipient from a program, the service recipient may elect to receive services from another service provider at any time. Personal choice and the option to choose another service provider are fundamental rights for people receiving services through DDSN.

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